SEPTEMBER 2018 E-NEWSLETTER

Subject: *SUMMER COMES TO AN END, SCHOOL BEGINS AGAIN …..*

ARTICLE 1 - Introduction

Welcome fall! For many, September can be a great opportunity for a fresh start, whether it's a new school you are attending, a new job you are starting or a new city you are moving to, the end of the summer can be a brand new page to turn. However, this month also marks the beginning of a new school year. Going back to school can be stressful, not only for students who are preparing to spend the next 8-10 months studying, but also parents who also need to cope with these changes as well. Especially when battling lupus, you may find yourself dealing with more flares due to longer days, less sleep and increased stress -- although this is normal, it does not make it any less inconvenient.

Last month, we shared some tips on what teachers should know about a student living with lupus, including the possibility of an Individualized Education Plan, or IEP. This month, we bring to you some more information about an IEP, what it entails and where to find more information. With lupus, there are many individualized symptoms and unexpected flares hence; having this set up at beginning of the year can prove to be very helpful later on. As a parent with a child who has lupus, there are different ways that you can inform your child about their condition, as outlined in the article "Tips for teaching children and teens about their lupus", no matter what age they may be!

ARTICLE 2 – BYRON WILSON &THE EXTREME FABULETTES!

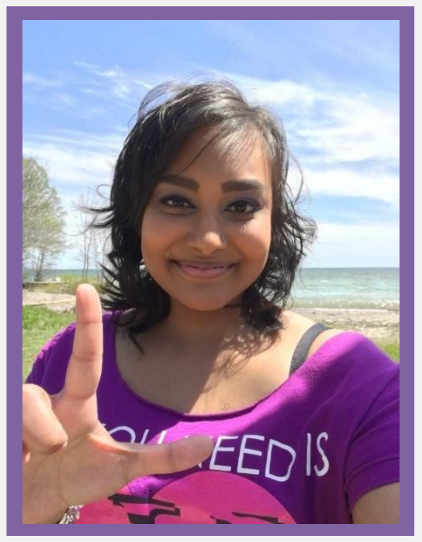
On July 21st& 22nd The Extreme Fabulists, helped to raise awareness and support for Byron Wilson who was just diagnosed with third stage of lupus at the age of 31. This year in particular presented many challenges for Byron and so, he looked to his community for support. The female impersonating event travels all around Ottawa Valley to raise money for local charities and this time, Byron chose Lupus Canada to support!

This two night event show at his local community of Carleton Place Ontario helped to educate individuals about lupus, explain his personal struggles with the disease as well as, how he will start to make changes to better his own life. Tanya Carlton, Lupus Canada's President, attended the event to support Byron and spoke about the importance of such events, not only for the lupus community, but also in helping to engage everybody else!

The two-night event was a major success, raising $1,700 to support Lupus Canada and research initiatives. Byron's community stood behind him and helped to raise a voice for lupus. We would like to take this opportunity to thank Byron and everyone else who supported this event! In the coming months, Byron will continue to raise awareness with some other events and ideas he has up his sleeve!

Byron Wilson in
Support of
LUPUS
CANADA
Life Without Lupus

ARTICLE 3 – MY LUPUS STORY BY NAT SAMAROO



As a teenager we all expect to go to school be with our friends and have fun, figure out who and what we want to be. You know what they say those should be the best years of our lives, high school; parties, dating choosing a college and a career path, and just having a great time experiencing everything a teenager should. Well for me things became a little complicated and things definitely did not go the way I thought they would. Shortly after my 17th birthday I developed a rash on my face that looked like well butterfly wings, that's where everything just went downhill. Trips to the doctor, countless tests. Then results had confirmed I had or have S.L.E. I do have lupus. It's not easy to live with but I learned to deal and live my life with its ups and downs.

The next year another big flare hit and i was unable to graduate high school when I should have. However I held my head high and finished school a year later and actually got a job doing what I love and it happened to be my co-op placement. It was a job at a face salon, caryl baker visage doing make up, facials, and waxing. Make up is the best part though I love it. Working there was the best thing to ever happen to me at that point and I was doing well for a while, no big flares. I did their special training, it was a month long course, but the stress from it ended up giving me shingles really bad on my face, I had to get a personal portable pump to get my meds to get the virus taken care of. I got over that and continued to work. Then I went on a vacation to Cuba, and I wanted to drink, so I did, and well as lupines we shouldn't do that, not too much any way or not at all. I got Pancreatitis, and was in the hospital when I came back for a week and a bit. Other than that my flares were just pain every so often coming but nothing I couldn't handle.

Then lupus reared its ugly head and I began to feel sick all the time, my hand would cramp up and seize up while trying to do my job. I was having flare, a bad one that ended up taking me away from work and on disability. I was waking up unable to move, not able to get out of bed, go to the bathroom sometimes. But when I had good days I was able to work on the side for my old boss but could never get back to it without ending up in some sort of lupus flare, small or big. I was also diagnosed with lupus nephritis a couple years after my initial diagnosis and in 2011 things got really bad. My whole body started to swell, I was retaining a lot of water, my feet were so bad I couldn't wear shoes, they looked like elephant feet. I had horrible cough and I started getting bad shortness of breath after taking a few steps, or climbing a few stairs. I was using a puffer for pneumonia and was treated earlier that year, early summer. In September I found out I was in mild Kidney failure, and had to start chemo. The start of October 2012 I did my first round. Then by the next weekend, thanksgiving weekend in Canada, I just couldn't catch my breath anymore after a shopping trip with my friend. My parents called the ambulance and I went to the ER on Sunday. Monday, on Thanksgiving I just stopped breathing as they tried to put a catheter in me so I wouldn't get up to pee. I was put on life support. They induced a coma, and were doing 24 hour dialysis. The doctors told my family to prepare; they didn't think I would survive.

My family and friends filled the waiting rooms, support from strangers and friends on Facebook, praying for me. I woke up Halloween, surprised the doctors, they called me a miracle. My muscles and nerves were damaged and I couldn't move. I had to learn to do everything again, rebuild muscle. Muscle I still don't have coming on 6 years later. I got out of the hospital almost 4 months later on Valentine’s Day. It has been a rough road to try and get back to where I use to be. For my 25th Birthday I decided to have a fundraiser birthday party and raised just over $2000 for Lupus. Unfortunately I didn't enjoy the party the way I could have, feeling sick, I was getting shingles for a second time. I hate shingles, what a horrible, excruciating pain! After that things were just up and down, flares here there. I wake up in pain every day. Most days I manage, but there are days I just can't. Physically and emotionally. At age 26, Close to the end of the year, I fell and hurt myself only to find out I have a vascular necrosis of the hips, and need a replacement right away for the left side.

Just before my 28th birthday I had my replacement, which was last year January 2016. I ended up staring a YouTube channel, Living Lupine, to follow my fight, and my journey through surgery. The recovery was rough, but I made it through, better than ever. I am lucky to have a wonderful support system to get me through tough times, which is so important. The new hip has been like a whole new world for me. So much freedom to move around, I haven't had that in a long time. Finally I started trying to get back to being me, before lupus, trying to all that prednisone weight, and just get fit and healthy. That was until now, which I am currently trying to get over a flare that put me back on steroids. I did find out I have been experience fibromyalgia pain, suck painful stuff, my goodness. It really sucks, I had gone 2 years without any big flares, but now lupus is trying to knock me down, but I am fighting back with all my strength! Right now I am organizing the Walk for Lupus Ontario in Mississauga, trying to do whatever I can to raise awareness. Lupus won't win!

#lupussurvivor #lupusfighter #livinglupie

ARTICLE 3 – INDIVIDUALIZED EDUCATION PLAN

Source: http://www.edu.gov.on.ca/eng/general/elemsec/speced/individu.html

When an Identification, Placement, and Review Committee (IPRC) identifies a student as an exceptional pupil, the principal must ensure that an Individual Education Plan (IEP) for that student is developed and maintained. An IEP must be developed with input from the parent(s)/guardian(s) and from the student if he or she is sixteen years of age or older. An IEP must be developed within thirty days of the placement of an exceptional pupil in a particular program. The parents/guardian(s) must be provided with a copy; the student must also be given a copy if he or she is sixteen years of age or older. An IEP may also be prepared for students who require accommodations, program modifications and/or alternative programs, but who have not been identified as exceptional by an IPRC.

An IEP identifies the student's specific learning expectations and outlines how the school will address these expectations through appropriate accommodations, program modifications and/or alternative programs as well as specific instructional and assessment strategies. The learning program provided for the student is modified on the basis of the results obtained through continuous assessment and evaluation. The IEP for an exceptional pupil who is fourteen years of age or older and who is not identified solely as gifted must also contain a plan for the transition to postsecondary education, or the workplace, or to help the student live as independently as possible in the community. In developing or reviewing the student's IEP, consideration must be given to any recommendations made by the IPRC concerning special education programs and services that may be particularly appropriate for meeting the student's needs.

To assist teachers and other support professionals in developing Individual Education Plans for exceptional pupils, the ministry has published The Individual Education Plan (IEP), A Resource Guide, 2004.

It is anticipated that, with appropriate special education programs and/or services, many students with special needs (whether formally identified or not), will be able to achieve the grade-level learning expectations of the provincial curriculum. The IEP will document any accommodations that are considered to be necessary for each exceptional pupil to succeed. Some students may require modifications to the learning expectations of the provincial curriculum in keeping with their special needs. Such students may be provided with modified expectations. A small number of students may require alternative expectations in order to succeed. Alternative expectations are those that are not derived from the expectations set out in ministry curriculum policy documents. Further guidance on curriculum adaptation and modification for exceptional pupils can be found in Ontario Secondary Schools, Grades 9 to 12.

ARTICLE 5 - TIPS FOR TEACHING CHILDREN AND TEENS ABOUT THEIR LUPUS

Source: http://www.resources.lupus.org/entry/teaching-children-and-teens-about-their-lupus

Explaining lupus to a child who has been diagnosed with this disease can be intimidating and difficult, depending on their age and maturity level. The following are some strategies you can use when talking with your child about their lupus. You should also bring your child’s health care providers into the conversation during visits since they may be more experienced in how to talk to children about lupus.

Preschool

At this age children are very literal. They may think, “I’m sick because I was being bad” or “I’ll be really good and I’ll get better.” At this time, children do not need a lot of information about their disease. However, there is no need for you to hide the facts.

Some important points to make when talking to your preschool-age child are:
- No one knows what causes lupus.
- Having lupus is not your fault.
- Lupus does not happen because you misbehaved or did something wrong.

Elementary School

Children in this age group can think concretely and abstractly. Although they are beginning to realize having lupus is not their fault, it doesn't relieve their stress. They may also expect parents to be able to "fix everything." You should allow them to ask questions and make sure they understand what you have told them.

Some important points to make when talking to your child at the elementary school age are:

- Lupus is not contagious. You can't catch lupus from someone or give it to someone.
- Lupus might make you feel very tired, sore, and/or achy. The doctor will give you medicines, and it's important to follow the instructions about when to take them so you can feel better as soon as possible.
- Some things will change, like being able spend a lot of time in the sun or participate in some activities.
- Be extra careful to wash your hands and stay away from anyone who is sick, so your body doesn't have to fight off extra germs.

Middle School

At this age your child can make rational decisions and judgments. You can begin to explain the more complicated physical effects of lupus. You can also begin to explain to your child, without becoming too technical, the names of their medications, the doses, what they are for, and how they work. When you think your child is ready you can ask the doctor to begin to speak directly to them.

Some important points to make to your child at the middle school age are:

- It's okay to ask questions about lupus or your medications, or even about personal issues.
- It is important that you always take your medications in the right amounts and at the right times each day.
- Try to focus on all of the things you are good at that your disease does not affect.

Don't give up on your goals and dreams.

High School

As a normal part of growing up, teenagers experience a wide range of physical and emotional changes as they move toward becoming independent adults. When a crisis occurs, such as a diagnosis of lupus, some teenagers may react with expressions of anger, frustration, and/or sorrow. Others may become withdrawn. However they react, teenagers, like all of us, will deal with a lupus diagnosis in their own ways.

When serious medical conditions occur in teenagers, you and your child's doctors must begin by making all the decisions. Once the disease is stabilized, however, teenagers need to feel that their opinion is important in the decision-making process. This helps them experience some degree of control over lupus, as well as realize the impact of their choices. The more they understand lupus, the better they will be able to manage living with a chronic illness as they move into adulthood.

This is an essential time for you to listen and be as understanding as possible. You may want to consult your teenager's doctor about the best way to talk to your teenager about lupus. And you may find that honest and open discussion of your feelings will help your teenager to express his or her own feelings.

Teenagers may face difficulties in taking prescribed medications correctly and regularly. Together you can design strategies that help your teenager stick with the treatment plan. Especially when your teenager is feeling well, it's important to reinforce that inactive disease is a result of the medication and that the medication must continue for the long term. Encouraging they talk with a doctor or nurse may be useful.

Having a chronic illness that causes pain and fatigue can make teenagers feel left out of the life that friends and peers are leading. But even though they may not be able to take part in a favorite activity one day, it may be only a temporary setback. Helping teenagers to focus on the many things they can do, rather than what they cannot do, is a good strategy.

ARTICLE 6 – RECIPE FOR BACK TO SCHOOL: WHOLE WHEAT CAPRESE PASTA*Source: http://gethealthyu.com/recipe/whole-wheat-caprese pasta/*

Prep: 5 mins
Cook Time: 20 mins
Serves: 4

Ingredients:

- 8 oz. whole wheat pasta
- 1 tbsp. olive oil
- 4 cups cherry tomatoes, halved
- 3 garlic cloves, minced
- Salt and pepper
- 3 tbsp. balsamic vinegar
- 4 cups spinach
- 1/4 cup basil, chopped
- 4 oz. fresh mozzarella, chopped

Directions:

1. Cook the pasta until al dente. Reserve ½ cup pasta cooking liquid. Drain and set aside.
2. Heat the olive oil over medium heat. Add the tomatoes. Season with salt and pepper. Cook for 4-6 minutes until tomatoes begin to soften, stirring often.
3. Add the garlic and cook for 2 minutes until fragrant.
4. Add the balsamic vinegar and spinach. Cook about 1 minute until spinach wilts.
5. Add pasta and stir to combine. Add pasta water if the pasta seems dry.
6. Turn off heat and stir in the cheese and basil. Drizzle with extra balsamic vinegar and add salt and pepper to taste.